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# *They Lift My Spirit Up*: Stakeholders' Perspectives on Support Teams for African-Americans Facing Serious Illness

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## Abstract

**Background—**Active social and spiritual support for persons with cancer and other serious illnesses has been shown to improve psychological adjustment to illness and quality of life.

**Objective—**To evaluate a community based support team intervention within the African-American community using stakeholder interviews.

**Methods—**Support team members were recruited from African-American churches, community organizations, and the social network of individuals with serious illness. Support teams provided practical, emotional and spiritual care for persons with cancer and other serious illness. The intervention was evaluated using semi-structured interviews with 47 stakeholders including those with serious illness, support team volunteers, clergy and medical providers.

**Results—**Stakeholders report multiple benefits to participation in the support team; themes included provision *of emotional and spiritual support, extension of support to patients' family*, and *support complementary to medical care*. Reported barriers to participation were grouped thematically as desiring to *maintain a sense of independence*, and *normalcy; limitations of volunteers* were also discussed as a barrier to this model of supportive care.

**Conclusions—**This qualitative evaluation provides initial evidence that a support team intervention helped to meet the emotional and spiritual needs of African-American persons with cancer or other serious illness. Volunteer support teams merit further study as a way to improve quality of life for persons facing serious illness.

### Keywords

Support Teams; cancer supportive care; spiritual support; community based participatory research; social support

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## Introduction

Persons with serious or potentially life-limiting illness have profound needs for supportive care, including practical, emotional and spiritual dimensions. Social support may aid psychological adjustment to illness[1]; spirituality is an important element of supportive care for many persons with cancer and other serious illnesses. [23] In particular, African-Americans may recognize more spiritual needs in relationship to cancer supportive care.[4,5] The need for support may be magnified for African-Americans by health disparities. Culturally appropriate supportive care which integrates spirituality, may improve quality of life for patients with cancer[2].

Supportive care may be added to formal health care, or may enhance existing community-based sources of support, as in peer support interventions. The support team model is an innovative form of community-based support adapted to the needs of seriously and chronically ill individuals. The basic model of a support team focuses on helping one person to meet a variety of needs and includes elements of peer support, focusing on the abilities of each team member.[6] Support team volunteers work together to provide practical, emotional, and spiritual support to a person who is open to receiving assistance.[6,7] Volunteers offer to assist in a capacity they are comfortable with, in a coordinated way.[8] Our research team has demonstrated the feasibility and acceptability of volunteer support teams for African Americans with cancer, called Circles of Care.[6] The support team model, developed in 1994 at the University of Alabama for improving supportive care in patients with HIV, has only been described in two other peer-reviewed studies prior to its use in the current research: a support intervention for caregivers of persons with Alzheimer's disease[9] (AD) and a church-based home-delivered meals program.[7] The intervention for caregivers of persons with AD demonstrates the ability of the model to provide support to caregivers in the organization of finances, personal care needs, and improvement of depression, while the meal delivery intervention demonstrates how the support team model can successfully be implemented using existing social-capital networks.

The aim of this research is to evaluate the Circles of Care volunteer support team intervention using narrative interviews with diverse stakeholders to understand the potential benefits and barriers of support teams.

## Methods

### Circles of Care Intervention

Circles of Care is a community based participatory research intervention which used the support team model to improve supportive cancer care for African-Americans. At the time of this evaluation, a network of 120 volunteers in support teams had been recruited and trained to create support teams to provide health information and practical caregiving to 41 African Americans facing serious illness. Support team members were recruited from African-American churches, community organizations, or the social network of the individual with serious illness. The intervention was conducted in a 3 county area of central North Carolina from July 2008 to July 2010 and was led by investigators from University of

North Carolina at Chapel Hill Schools of Medicine and Public Health and Duke University Divinity School. Collaborators included three community-based non-profit service organizations – the Community Health Coalition, Project Compassion, and CAARE, inc. Community members provided insight during the conception and implementation of the intervention as contributing members of a community advisory board. Additional details of the Circles of Care support team project have been published.[6]

## Support Team Development

Support team volunteers elected to participate in either a 3-hour team member training or day-long team leader training. Content included information on physical, emotional and spiritual pain, supportive approaches, and how to access palliative care and hospice and advance care planning. In leader training, participants practiced team-based approaches for communicating with, advising, and supporting persons who faced serious illness. Support teams included 6–10 trained volunteers who agreed to work together to support one or more individuals with advanced illness. Support teams were matched with individuals requesting supportive care based upon geography, existing relationships between individuals and the interests and skills of team members and identified support needs.

## Data Collection

**Participant interviews—**Stakeholders, including trained volunteers, persons with illness who accepted a support team and those who declined, family caregivers, clergy, and health care providers were approached following engagement within the support team intervention. Eligibility criteria included individuals age 20 or older who had prior experience with the Circles of Care support team intervention, including patients who had been offered a support team and decided against it. Purposive sampling methods were used to guide the selection of participants. All eligible stakeholders were invited to participate; enrollment continued until each stakeholder group was represented by more than one participant.

Interviews were semi-structured, conducted in a private setting, and audiotaped. Interviewers were trained to use a written interview guide structured around these key questions: "What does a support team mean to you? How does this support differ from getting help at a cancer center or doctor's office? Do people facing serious illness need support?" These questions were followed by probes exploring practical, emotional, spiritual support, quality of life, advocacy, and help with cancer or disease-specific resources. At the conclusion of the interview, participants were asked if they had recommendations for improving the support team model. Patients referred for support teams who did not participate in the study were included for the identification of barriers to participation; questions were the same as for all interviews. These individuals were aware of the support team model, and responded based on their decision not to accept this form of peer support.

Support team members and persons with serious illness provided demographic and health data in a brief written survey at the time of study enrollment. They gave verbal informed consent for the use of de-identified descriptive information. Some persons with advanced illness elected to have members of their support team or family members present during their interview session. All research methods were reviewed and approved by the University of North Carolina at Chapel Hill School of Nursing and Public Health Institutional Review Board.

**Qualitative Analysis—**Audiotaped interviews were transcribed verbatim and identifying information was redacted. The final transcripts were reviewed for accuracy by the research team and the data were imported into Atlas 6.0 for coding and the construction of memos.

Analysis methods used a grounded theory approach to explore and organize themes. Three readers used iterative consensus coding to identify initial thematic groupings that emerged from the interviews. Categorical codes were defined in a series of consensus discussions, including support team barriers, support team benefits, facilitators of support teams, support team supplementation of medical care, support team unique qualities, call to service, recruitment, cancer journey, and connection. Once a unified coding scheme was agreed upon, two readers applied the codes to all transcript text and the third reader resolved any conflicting codes. All readers then reviewed coded qualitative transcripts and constructed memos to represent a synopsis of the data representing a single categorical code.

For the analysis presented in this paper, the codebook and all memos were reviewed to address the objective of understanding the benefits and barriers to the Circles of Care support team intervention. All coded text was reviewed to gain further insight into thematic groupings. Selected themes, derived from subgroups of the categorical codes, were explored in depth for the purpose of the analysis. All text supporting benefits and barriers to the support model were examined, and illustrative quotations selected with attention to inclusion of multiple perspectives.

## Results

A total of 47 individuals participated in the semi-structured interview sessions. (Table 1) Most participants in the interviews were African American (86%) and female (77%). The age range of participants was from 20–89 years of age. Participants' roles in the Circles of Care project included support team volunteers (57%), person with advanced illness (21%), medical providers (13%), caregivers (11%), and clergy (9%). Five participants were identified with than one role in the Circles of Care project; for example, one clergyman was also a support team member. Three of the twenty-seven support team members were also cancer survivors.

### Perceived Benefits of the Support Team

Stakeholders described many benefits of the support team. Major themes regarding benefits included the provision of *emotional/spiritual support, the extension of support to family*, and *support complementary to medical care*. Each theme is described below in more detail, with related quotations from interview participants.

**Provision of Emotional and Spiritual Support to Persons with Serious Illness —**In this participant sample, mainly comprised of church-attending African-Americans, spiritual and other emotional aspects of care were viewed as important, yet not available in a cancer center or doctor's office. The importance of having spiritual needs met and the role of support teams in facilitating spiritual support was voiced by nearly all participants in these interviews. One support team member describes how a support team provides "…encouragement that has kind of a spiritual overtone overtly…it may be prayer and again that's not something that people are typically going to get along the continuum of care from institutions or health care facilities or at a cancer center or anything like that."

Persons with illness in the intervention described how support team care helped to alleviate symptoms of depression. Descriptions of depressive symptoms in these interviews included vernacular such as feeling down or low; for example, one person with serious illness said, "Before they started coming, I was down and out…. But since they've been coming, it's done lift me up. I don't feel down no more. I just feel good and happy since they've been coming. They lift my spirit up. "

Another person with serious illness noted how her support team relieved feelings of suicidal ideation. She said, "…I have thought about killing myself. I've been just down because the sickness and all, you know, has been bothering me and all that and when they [support team volunteers] come along and start talking to me, all that left me and now I thank God for it; none of that don't cross my mind no more. All I'm doing is looking up towards the Lord. He's the only one that can help me to bring me through."

Persons with illness also expressed other benefits including encouragement, motivation, fostering the will to live, and alleviating feelings of loneliness. One described the unique role of one of her support team member, in encouragement and emotional support; "Well the support team has been there for me to talk more about cancer… because one of my support members has gone through the same thing and she talks to me…"

Other persons described the support team as filling emotional needs when family members fell short. One person with advanced illness reflected, "I got a Mother's Day card from one of them and it was the only Mother's Day card I received and I do have a child…"

Healthcare providers who participated in the Circles of Care support team intervention also echoed sentiments concerning the importance of emotional and spiritual support. A physician who had referred patients said, "I believe that one of the most important roles that a support team member can play as it pertains to the spiritual life of the friend is to be a sounding board, to be someone who accepts that person's journey and is able to encourage the friend to tell the story or the stories of his or her spiritual journey"

**Extension of Support to Families—**Recipients of Circles of Care support and support team members alike noted that benefits often extended to the children of persons with advanced illness. Support provided to children included emotional and practical needs, including transportation to shopping centers, recreational activities and personal grooming appointments. One person with serious illness noted "… they [support team] help my kids see what I'm going through; I have lung cancer, I was diagnosed with it and they let people know, let my children know that it's a lot of love around a lot of people".

A support team member said, "It was very inclusive of the family. Well it kind of took some of the pressure off of them… when your loved one is going through some stuff, it's stressful. There's a lot of pressure on the family."

A pastor described the potential benefit of the support team providing support for the family by sharing knowledge about things to anticipate in the trajectory of severe illness. "… I can recall as a caregiver for my father-in-law, there were things that my wife and I could not do or had to learn to do and it would have been very beneficial to us to have somebody to come in and help us with, with a lot of the things that we needed to do… we learned by trial and error… "

Several participants also noted that caregiver burnout may be addressed by the intervention. A health care provider noted that "…the realities of dealing with an ill person are that it is very draining in terms of time, in terms of emotional investment, in terms of trying to understand the illness and then get proper treatments and interventions … one of the greatest thing about the practical support that our support teams give is that it allows that caregiver to have respite…"

**Support Complementary to Medical Care—**Interview participants described several perceived gaps in the support provided by traditional medical care, and reflected on ways the support team addresses these gaps by providing consistent and coordinated support. The support team was perceived to be a necessary facilitator and complementary to medical care. Several support team members acknowledged differences between a support team and a cancer center support group. One mentioned, "Well I think a lot of the support groups at different facilities, especially a doctor's office or a cancer center, they're designed for the patient to come to them in most cases … a lot of these support groups at the cancer centers and the doctors' offices, don't get utilized to their full potential because that requires that person to come out."

Another support team member emphasized the importance of support at any time of day, saying "They [Circles of Care support team] make sure that the person receives the support they need, psychosocial, whatever kind of support they need beyond the, the business day."

Another support team member commented, in reference to helping a person with cancer, "… if she had other people to facilitate some of those activities, she would have a much richer and much more meaningful life at home despite dealing with her cancer and cancer pain. None of those things are things that doctors and nurses can help her with."

The support team provides assistance in companionship and patient advocacy and may even improve the perceived quality of care for the person with serious illness. For example, one support team member said, "… People that have someone to talk to, someone to help write down discussions that occur between the physician or provider and the patient, it's a second set of ears, …those people tend to do a lot better through treatment as well as in the recovery phase."

Some stakeholders also described the ability of a support team to integrate emotional and spiritual care during medical care episodes. One support team member noted, "That person who is in the emergency room with a pain in their bone from cancer should not be alone. … They need somebody who's their advocate. … They need .. meaningful and maybe even prayerful support to get through that pain experience"

### Perceived Barriers to Circles of Care Support Teams

Persons with serious illness and support team members describe potential barriers to support including the desire of persons with serious illness to *maintain a sense of independence*, and *maintain a sense of normalcy*. The *limitations of volunteer support team*s were also described as a potential barrier.

**Maintenance of Independence—**The tension between a desire for independence in the setting of serious illness and an acknowledgment of the need for practical and emotional support was described by persons with illness. One person with serious illness said, "I don't think a support team should say this is how we're going to outline our care for you because that may not necessarily fit with what I want." Persons with illness also indicated that retaining the autonomy to ask for support when needed and not feeling obligated to accept the help that is offered to them through the support team was an important barrier to participation. One person with advanced illness said, "I don't envision a support team as being for me, constantly in my space, constantly calling, constantly checking. I don't think I need that; even though I'm a cancer patient long term…"

**Desire for Normalcy—**In addition, persons with illness identified a desire for normalcy and a rejection of support on the basis that it signals a loss of hope or vitality. One person with advanced illness, who had accepted a support team for themselves, imagined this acceptance would not be universal, saying "I don't want you coming into my space because your presence could mean a death sentence. Well I'm to the point where I have to have Circles of Care or other groups like Circles of Care coming in and some patients are not to that point yet. They want to live a normal life."

**Limitations of Volunteer Support—**Finally, many stakeholders acknowledged that volunteer support has its limits, and that this may be a barrier to wide acceptance of support teams. Persons with illness or support team members may both lack understanding regarding the scope of volunteer support teams and what they are capable of providing. Among some support team members, there was a perceived limitation in preparedness to handle the complex issues of terminal illness. One support team member commented, "A social worker or somebody should've been in charge of this case so that we had a source with all the information… because… she [person with illness] didn't know what tests she was going to have, she didn't know about her meds, she was confused last week even…"

## Discussion

This qualitative evaluation of a community based and faith centered support team intervention for persons with serious illness provides evidence to support its potential benefits. Stakeholder interview responses highlight the benefits of support teams as a model to blend practical, emotional and spiritual support for persons with serious illness. This peer-led, community-based form of supportive care was seen by stakeholders as meeting needs beyond the scope of traditional medical care. Barriers to participation include balancing the need for help with a need for independence and a sense of normalcy. Specifically acknowledging the importance of autonomy, normalcy and independence within support team member training and in recruitment strategies for persons with illness may reduce the barriers to participation. African American cancer patients, and all persons with serious illness, will accept supportive care at the pace they judge appropriate for themselves. Early awareness of support teams, and repeated opportunities to consider supportive care may help patients who feel needs are currently met or are reluctant to acknowledge a need for supportive care.

The socio-ecological theory of community health promotion acknowledges the role of trusted sources within social networks[11] and highlights the importance of maintaining a strong community presence in an intervention such as a support team. The utilization of existing social structures and community partnership were instrumental in the development and implementation of this support team intervention. This model can be contrasted with cancer support groups, which also provide access to information, emotional and spiritual support, but do not provide the practical support and home presence that may be required to reach those patients with serious illness.[10] Peer support may be based in social networks, as when lay health advisors serve their communities, or in health care organizations, through patient navigators.[12] However, traditional peer support providers who work one-on-one with patients may find their abilities to provide assistance overwhelmed by the greater needs of patients with serious illness.[6]

The applicability of this program evaluation is limited by heterogeneity within the African-American community, regional variability, and limited male participation in the intervention. Selected participants from each level of participation within the support team model were interviewed to obtain a well-rounded view of the model and we also recruited individuals who were referred to participate in the model but did not participate in the actual intervention. As support needs are often dynamic in nature, future evaluation of this intervention will include longitudinal analysis of support needs of persons with illness and how those needs can be met.

In conclusion, this volunteer support team intervention facilitated the development of an innovative form of peer support that was coordinated yet flexible enough to adapt to the needs of individual. The support team model allowed volunteers within existing community structures, including churches, to combine efforts and deliver supportive care. The sense of fulfillment among volunteers may be an important motivator in sustaining this type of intervention. Culturally sensitive interventions grounded in the principles of palliative care and social support, such as the Circles of Care intervention, may improve understanding of and access to cancer support among African-American patients and their faith communities.

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## Table 1

Characteristics of Interview Participants

| | N | % |
|---|---|---|
| **Gender** | | |
| Female | 36 | 77% |
| Male | 11 | 23% |
| **Age (years)** | | |
| 20–39 | 6 | 13% |
| 40–59 | 18 | 38% |
| 60–79 | 5 | 11% |
| 80–89 | 1 | 2% |
| Age not reported | 17 | 36% |
| **Race** | | |
| African American | 42 | 89% |
| Caucasian | 3 | 7% |
| Asian | 1 | 2% |
| Other | 1 | 2% |
| **Role of Participant**[*] | | |
| Caregiver | 5 | 11% |
| Clergy | 4 | 9% |
| Person with advanced illness | 10 | 21% |
| Healthcare Provider | 6 | 13% |
| Support Team Member | 27 | 57% |

[*] Five participants identified themselves with more than one role, so percents add to more than 100%. Two persons with advanced illness did not participate in the support team model but agreed to participate in an interview.

## Table 2

Selected themes identified in the semi-structured interviews relating to benefits of the Circles of Care Support Team intervention.

| **Selected Themes** | **Participant(s) endorsing theme** |
|---|---|
| **Perceived Benefits of Support Team Model** | |
| Emotional and spiritual support to persons with serious illness | Support team members, persons with illness, clergy, caregivers, providers |
| Extension of support to the family of persons with illness | Support team members, persons with illness, clergy, providers |
| Complementary to medical care | Persons with illness, providers |
| **Perceived Barriers to the Support Team Model** | |
| Maintenance of independence | Persons with illness |
| Desire for Normalcy | Persons with illness |
| Limitations of Volunteer Support | Support team members |